

HB 5667  
March 3, 2008

Chairman Handley, Chairman Sayers, and members of the Public Health Committee:  
Thank you for the opportunity to testify in support of HB 5667.

My name is Valerie Wozniak. My 7 year old daughter, Lauren, was diagnosed with Type 1 diabetes when she was just 21 months old. Lauren wears an insulin pump to get the insulin she needs to stay alive.

The insulin pump continuously delivers insulin to the body through a tiny tube which is connected to the body. Then, every time Lauren eats, we need to enter some information into the pump so that it can calculate the proper dosage of insulin to cover the food – then a burst of insulin is delivered on top of that steady stream. Conversely, when Lauren exercises (at recess or during gym class), we must cut back on the insulin she's getting so that her blood sugar numbers don't go too low. In the course of a day, the pump is handled many times.

When Lauren went on the insulin pump at age 3, she was attending the Capitol Child Development Center - the on-site daycare facility for the children of legislators and state employees. Her day care providers quickly learned how to handle the pump and did all necessary adjustments as is allowed under the law for daycare providers.

For the first year and half Lauren was in elementary school the teachers and aides were also trained to support insulin administration through the pump and make other necessary adjustments. This worked fabulously for Lauren and for the school, until the Department of Education got involved.

Based on Department of Public Health regulations, the Department of Education ruled that only the school nurse is permitted to touch an insulin pump or in any way handle the pump. Although teachers and aides are permitted to, and indeed do, perform blood glucose checks, compute carbohydrates, assess physical activity levels and evaluate Lauren's physical status, they are not permitted to enter data into the pump. This means that each time the pump must be touched, the nurse must be called into the classroom or Lauren must go to the nurse's office. However, an aide or teacher must tell the nurse what to enter, since the nurse was not actually present to assess the food intake or physical activity that would require an adjustment.

Frankly, this is silly. But it also has the potential to diminish the quality of Lauren's care, because, if the nurse is occupied with another sick child in another part of the school, the adjustment to the insulin pump is delayed.

In addition, it's a disruption to the educational environment. Either the nurse disrupts the class by coming in or Lauren misses instruction time by going to the nurse's office.

Last, it's more costly to the school in terms of staff time, because both an aide and the nurse must be involved, rather than just the aide who is already in the classroom. Although, in the daily classroom, this may not add up to much, it does require a nurse to travel with Lauren on field trips and even on the bus to and from school.

Let me note that Lauren is not the only child affected by this ruling, as we know several other children with diabetes who use an insulin pump. They cannot now easily participate in extracurricular activities and field trips because of this ruling.

In sum, we are not asking for mandates. We are asking for opportunities. The parents and the school should be able to determine what is in the best interest of the child based on that individual child's needs and on the district's resources. The proposed legislation would not require anything new of schools, and would not create a mandate on schools, but would give schools the flexibility to meet the needs of these children in a safer, and healthier and less expensive manner.

I've included letters from Dr. Tamborlane, a nationally renowned pediatric endocrinologist from Yale University, Dr. Estrada, an endocrinologist from CT Children's Medical Center here in Hartford, and Deborah Holtorf, a pediatric nurse practitioner specializing in diabetes care from Joslin Diabetes Center in Boston. In all cases these medical professionals endorse the fact that non-medically trained staff can and should be allowed to enter data into the pump.

Thank you for your consideration of HB 5667.



January 12, 2007

University of Hartford Magnet School  
196 Bloomfield Avenue  
West Hartford, CT 06117

To Whom It May Concern:

As per previous correspondence, my patient, Lauren Cassot, is allowed to self-administer insulin. I understand that there is some question as to the definition of self-administration with regards to the insulin pump.

I have reviewed the accommodations of Lauren's 504 plan and find them to be comprehensive and appropriate to provide the necessary care to prevent short-term and long-term complications caused by blood sugar levels that are too high or too low. The accommodations are in compliance with the American Diabetes Association's Safe At School Principles which are endorsed not only by me, but also by the American Academy of Pediatrics, American Association of Clinical Endocrinologists, American Association of Diabetes Educators, American Dietetic Association, Children with Diabetes Disability Rights Education Defense Fund, Juvenile Diabetes Research Foundation, Lawson Wilkins Pediatric Endocrine Society, and the Pediatric Endocrine Nursing Society.

I fully support the approach which requires that the Primary Care Provider use the insulin pump to calculate and prepare the food and correction boluses so that Lauren can self-administer by pressing the "ACT" button. I understand that the Primary Care Provider is not a nurse, but is an adult trained in the behavior of the pump. This is a safe technique that is used by many of my patients.

Please do not hesitate to contact me with any questions regarding this matter.

Sincerely,

Elizabeth Estrada, M.D.  
Attending Endocrinologist  
Connecticut Children's Medical Center  
282 Washington Street  
Hartford, CT 06106  
FAX: 860-545-9376



**WILLIAM V. TAMBORLANE, MD**

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1/19/07

University of Hartford Magnet School  
196 Bloomfield Avenue  
West Hartford, CT 06117

To whom it may concern:

At the request of Lauren Cassot's parents, I have reviewed the letter sent to you by Dr. Elizabeth Estrada (copied below). I am in total agreement with everything in Dr. Estrada's letter.

Sincerely,

William V. Tamborlane, M.D.  
Professor and Chief of Pediatric Endocrinology

**Letter sent by Dr. Estrada:**

University of Hartford Magnet School  
196 Bloomfield Avenue  
West Hartford, CT 06117

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Sincerely,

Elizabeth Estrada, M.D.  
Attending Endocrinologist  
Connecticut Children's Medical Center  
282 Washington Street  
Hartford, CT 06106

January 28, 2007

University of Hartford Magnet School  
196 Bloomfield Avenue  
West Hartford, CT 06117

To Whom It May Concern:

I am writing from the perspective of a pediatric nurse practitioner specializing in diabetes care and a former school nurse of 14 years. I am currently employed at the Joslin Clinic Pediatric and Adolescent Unit. The majority of children in my current practice is of school age and is treated for type 1 diabetes.

Insulin pump therapy in this age group has been shown to improve blood glucose control and reduce the frequency of severe hypoglycemia (low blood sugar). The pump is pre-programmed by the family and medical team to give a constant basal (background) rate to meet the child's basic metabolic needs and to calculate a bolus dose to cover the grams of carbohydrate the child ingests and correct high blood sugar every 2-3 hours as needed. The user needs to enter the grams of carbohydrate and current blood sugar. Most young children understand the "button pushing" needed to deliver a bolus dose of insulin, but because they can be rushed, are subject to normal developmental issues such as number reversal, inattention, and forgetfulness, we teach them that they are not allowed to deliver bolus insulin without the supervision of an adult.

Our position at Joslin Clinic is that the adult supervising use of an insulin pump needs to be trained in using the pump and basic diabetes management including performing a blood sugar check, treating hypoglycemia, and assuring that the child checks his or her ketone level per written protocol if the blood sugar is elevated so that a school nurse or parent is notified when follow-up is required. Since the pump is already programmed and inserted subcutaneously, we do not recommend that only a registered nurse can supervise its management. I currently have patients in my practice whose pump management is supervised by an aide, a school secretary, and in several situations a classroom teacher. Some of these children touch bases with the school nurse daily. Some do not have a school nurse available.

We strongly advocate for the presence of a school nurse to educate the adults assisting the child in pump management, to assist with problem solving, to manage emergencies, and to maintain communication with the child's family. Most of the children we care for, however, have 504 plans that provide for testing and treating blood sugar in the classroom so that the child does not miss academic time or continue to lower an already low blood sugar by walking to the nurse's office. The 504 plan may also specify that a

child not be required to lose time from lunch or recess to treat diabetes. Supervision by a trained adult relieves the need for a nurse to be in several places at once.

The risks associated with programming an insulin pump by a trained adult are minimal. Giving too large a bolus can result in hypoglycemia, but so can the basal insulin that is being constantly delivered by the pump, if the child is more active than usual. All adults working with a child in school should be trained in recognizing, confirming (children who are experiencing low blood sugar may be too shaky or confused to use the glucometer independently), and treating hypoglycemia.

Please feel free to contact me if you have any additional questions or concerns.

Sincerely yours,

Deborah Holtorf, MPH, MSN, NP  
Pediatric and Adolescent Specialist, BC-ADM

Recent presentations and publications:

Holtorf D. Type 1 diabetes in children and adolescents: an overview of real-life issues, Advance for Nurse Practitioners, 2007; 15 (1): 39-42.

National Association of School Nurses Annual Meeting, 07/2005

“Diabetes in Children and Adolescents: Changing Concerns”

“Caring for the Student with Diabetes”